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## **INTRODUCTION**

Greater Trochanteric Pain syndrome (GTPS) is a debilitating condition causing pain on the lateral aspect of the hip (Grimaldi et al., 2015). It affects up to 23.5% of women and 8% of men between 50-75 years old (Segal et al., 2007).

The LEAP randomised controlled trial (education plus exercise versus corticosteroid injection use versus a wait and see approach for gluteal tendinopathy) has demonstrated that a programme of education and exercise targeting the gluteal muscles is more clinically effective for patients with GTPS than cortico-steroid injection and wait-and-see approaches (Mellor et al., 2018). However, data suggests that patients who present to the National Health Service (NHS) with a primary complaint of GTPS are different to patients recruited to the LEAP trial, as they demonstrate higher levels of pain, poorer quality of life and higher BMI (Stephens et al., 2019). These results likely reflect the fact that the NHS is a free to access public health service in the UK, whereas participants in the LEAP trial were mostly community dwellers, not seeking care for their pain. These findings are important, as patients who have higher levels of pain, higher levels of disability, persistent symptoms and co-morbidities; have more complex presentations and report poorer clinical outcomes for other musculoskeletal complaints (Scherer et al., 2016; Valentin et al., 2016; Artus et al., 2017).

Persistent musculoskeletal pain has been associated with a range of biopsychosocial factors including, psychological, cognitive, lifestyle and social factors (Alizadehkhayat et al., 2007; Kelly et al., 2011; Feldman et al., 2015). These factors might act as barriers to recovery and may need to be considered as part of complex interventions to achieve the best outcomes for patients with persistent musculoskeletal pain (Vibe Fersum et al., 2013; Lin et al., 2019).

Qualitative interviews can offer valuable insights into the lived experience and perceptions of patients with persistent pain, which can help generate new knowledge (Toye and Jenkins, 2015). This knowledge can help researchers understand a problem, identify priorities and find solutions

that make a difference to the future implementation of an intervention in the real world (O’Cathain et al., 2019).

No qualitative research has explored the experiences of patients living with GTPS. This qualitative study aims to provide insight into the experiences and perceptions of individuals with a primary complaint of GTPS to gain understanding and inform a programme of intervention development for testing in a future randomised controlled trial.

## **METHODS**

Ethical approval for the study was granted by the London - Surrey Borders Research Ethics Committee, 19<sup>th</sup> November 2018 (REC reference 18/LO/2014). All participants gave written informed consent before data collection began. The study is reported in accordance with the consolidated criteria for reporting qualitative (COREQ) research (Tong, Sainsbury and Craig, 2007).

### **Study Design**

A qualitative design using in-depth semi-structured, telephone interviews was undertaken to explore the experiences of people living with GTPS. The theoretical perspective that informed this research was post-positivism as this was best suited to address the aim of the research (Creswell and Poth 2018).

### **Participants**

All adult patients ( $\geq 16$  years) on the physiotherapy waiting lists (November 2018 – January 2019) at a single NHS elective orthopaedic hospital following a diagnosis of GTPS and referral from a specialist consultant-led clinic were purposively sampled. GTPS is an umbrella term used to cover the array of diagnostic labels used in clinical practice, including gluteal tendinopathy, trochanteric bursitis and lateral hip pain (Fearon et al., 2013; Long, Surrey and Nazarian, 2013) and as such, all patients with these diagnoses were considered eligible.

Following identification from the waiting list by the lead author, patients were sent the study information sheet and consent form by post. Those who returned a completed consent form were contacted via telephone to check their eligibility and subsequently booked for an interview. Patients were deemed ineligible if they were unable to speak and understand the English language due to limited research resource. Patients who had previously been diagnosed with an inflammatory condition; were suffering a systemic or infective illness, or had been given a diagnosis of

Fibromyalgia, polymyalgia or persistent multi-joint pain were also excluded to try and ensure the interviews focussed on the experience of living with GTPS and not, other long-term conditions.

Twenty-seven patients were sent the study information, from which thirteen patients replied. Two patients did not meet the eligibility criteria and one patient was not contactable, which provided the initial recruitment target of ten patients. The recruitment target was based on previous qualitative studies which aimed to understand the experiences of patients living with peripheral musculoskeletal pain which reported data saturation with 9–10 participants (Cuff and Littlewood, 2017; Gillespie et al., 2017; Smith et al., 2018). However, recruitment would continue until data saturation was achieved by sending follow-up invites to non-responders as required.

### **Data collection**

Semi-structured telephone interviews were conducted by the lead author who was unknown to participants. The lead author is a male clinical academic physiotherapist, with experience of conducting semi-structured qualitative interviews. The wider authorship group also included three academic physiotherapists (CL, GY, SON), a clinical physiotherapist (CH) and a member of a Patient and Public Involvement and Engagement (PPIE) user group (CM). The lead author was guided by an interview schedule (Appendix 1) which was designed by the authorship group (GS, SON, CL). The topics that shaped the questions used in the interview schedule were identified from initial conversations between the wider author group, a PPIE user group meeting (conducted by the lead author at the site of the study) and from a review of the literature. This information was collated by the lead author and shared with co-authors (SON, CL), including the audio recording of the PPIE user group meeting. A final discussion was held between the same co-authors, where five sub-themes were established which were likely to generate data which could usefully inform future intervention development.

1. Living with persistent pain
2. Understanding of the problem and pain

3. Experiences of previous treatment
4. Beliefs about activity and exercise
5. The future

The interview schedule was used to direct the interviews by providing *a priori* topics to be explored in relation to the aim of the study. The interview schedule was tested in two pilot interviews, conducted by the lead author with work colleagues. This familiarised the lead author with the questions and allowed feedback from colleagues and the author group. The interview topics did not change as a result of the piloting, but the wording of some questions were altered to make them more open-ended (Appendix 1). The interviews were conducted over the telephone and were recorded on a digital Dictaphone device. Field notes were made to document contextual information to supplement the transcripts. Further discussion was guided by the participant's response to these questions to ensure sufficient flexibility to allow the exploration of new and unanticipated issues.

### **Data analysis**

The Framework Method was selected to analyse the data as it is a systematic approach to qualitative analysis specifically used when, as in this study, the objectives of a study are specified prior to analysis and is theoretically congruent with a post-positivist perspective (Creswell and Poth 2018; Smith and Firth, 2011). It outlines seven stages of data analysis (Table 1), which can be applied to a purely deductive analysis, where data is solely applied to pre-determined themes; however, it can also allow for inductive analysis or a combination of both (Gale et al., 2013). We initially used a deductive approach of analysing the data, using the five topics which informed the interview schedule as the framework to analyse the data. However, transcripts were then re-analysed to ensure that no new themes occurred which needed to be added to our framework. The data was

then coded and analysed to identify whether data saturation in relation to the study objectives had been achieved. The data was finally interpreted (step 7 of the Framework Method) to identify final themes which could directly inform a programme of intervention development (Table 1).

One of the co-authors (CM) was a PPIE user group member, who as a member of the public, was able to provide valuable insights and a different perspective to the phenomena emerging from the data.

**Table 1. How the framework method was used to analyse the data**

<b>Stage of Analysis</b>	<b>Description</b>
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1. Transcription	Interviews were transcribed by a professional medical secretary and checked against the audio files for accuracy via the lead author.
2. Familiarisation with the interview	All audio files were re-listened to and all transcripts were re-read. At this point contextual and reflective notes were taken by the author group.
3. Coding	Each transcript was read line by line and codes were applied to passages that were felt to be relevant by the lead author and co-author (GS, SON). Passages were coded in relation to the pre-existing topics which informed the interview schedule. This process was supplemented by 'open coding' where passages that were felt to be interesting or relevant but did not fit within the pre-existing framework were coded as 'other'. This 'open coding' was used to ensure that important aspects of the data were not missed and to see if the pre-existing framework needed to be altered.
4. Developing the working analytical framework	Once all coding had been completed, lead authors (GS, SON, CL) met to analyse the coding, and determined that there were no new themes to add to the pre-existing framework relevant to the study objectives. This is a deviation from the Framework method of analysis which suggests that authors should meet after the first few transcripts are coded. However, as the analysis was largely deductive in this study, the author group were satisfied that this did not detract from the quality of the analysis.
5. Applying the analytical framework	The transcripts were then indexed using the codes relating to the pre-existing framework. The lead-author used the NVIVO 12 software to code the transcripts.
6. Charting data into the framework matrix	The coded data was entered into a final report which included references to the initial quotations so that the sentiments of participants were not lost. The author group was satisfied that data saturation in relation to the study objectives (to inform intervention development) had been achieved.
7. Interpreting the data	Interpretation of the emerging data occurred at regular meetings between the author group. The coded data was interpreted by the author group, to explore relationships between the categories and understand the phenomena which emerged from the data in relation to the study objectives.

## **RESULTS**



## Participants

A total of twenty-seven patients were identified and sent the study information, and ten patients (nine women, one man) were recruited to the study (Table 2). Ten telephone interviews, lasting up to 25 minutes and amounting to 223 minutes of audio recording, were undertaken.

**Table 2. Characteristics of the participants**

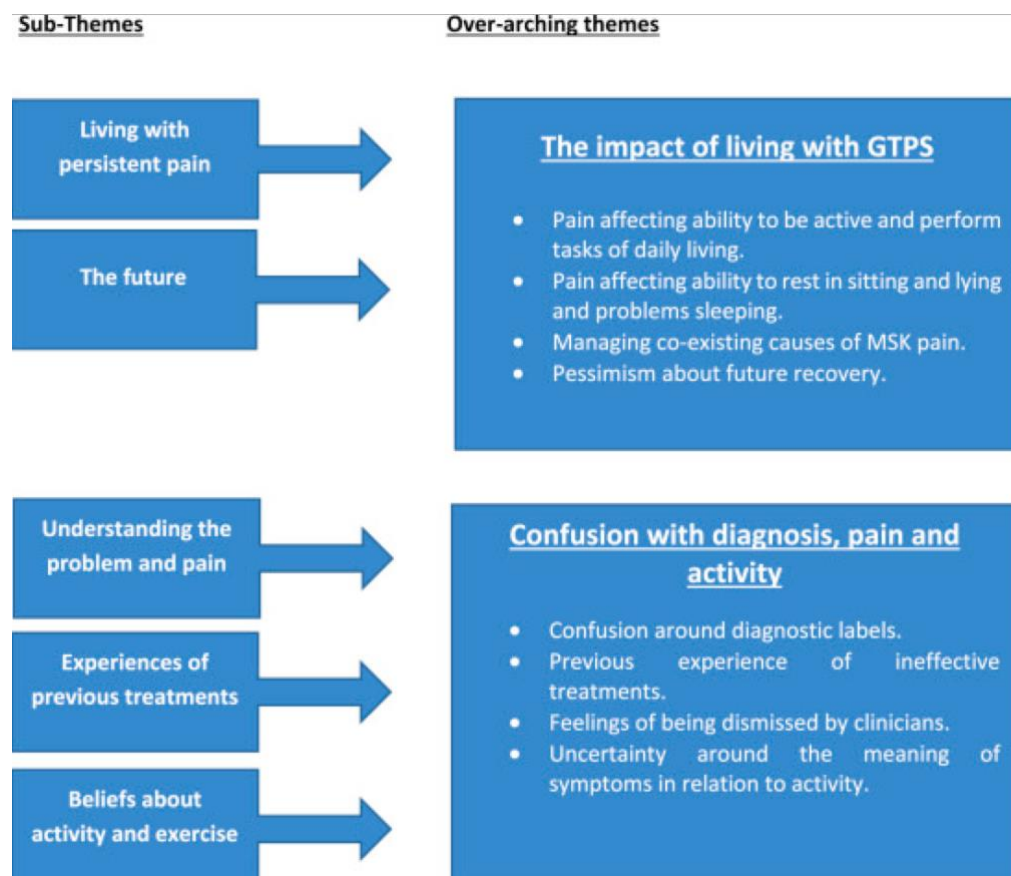
Participant	Sex	Age	Duration of symptoms
1	F	82	1 year
2	F	43	5 years
3	F	73	6 years
4	F	59	2 years
5	F	79	4 months
6	F	58	4 months
7	F	72	3-4 years
8	M	64	6 months
9	F	62	18 months
10	F	32	3 years

## Findings

Data analysis confirmed that data saturation had been achieved as no new themes emerged in relation to the study aim (Creswell and Poth, 2018). As such, it was felt that further or repeat interviews were unlikely to add new insights, which would inform the intervention development process.

Further analysis of the data within the pre-existing framework identified 2 new overarching themes which could directly inform a process of intervention development: 1) The impact of living with GTPS; 2) Confusion around diagnosis, pain and activity. Fig. 1 shows the relationship between the sub-themes which made up the pre-existing Framework and the over-arching themes which

emerged from it. Whilst these are presented separately there is overlap between the sub-themes and over-arching themes. Data is presented under the five sub-themes which made up the pre-existing framework. The numbers of participants who provided a particular response has been reported for questions directly asked to all participants, unless stated. Anonymised quotes are included to highlight the findings. Interpretation (step 7 of the Framework Method) of these findings in relation to the two overarching themes are presented in the discussion.



**Figure 1.** The relationship between the sub-themes and over-arching themes.

### **Living with persistent pain**

The majority of participants reported that their pain was intrusive as it often affected their activity, as well as their ability to rest, whereby sitting, lying and sleeping were commonly disturbed.

*"If I do a proper walk, it aches a lot, but then I can't sleep at night...I cannot lay on my side now or anything without enormous pain" [P7]*

*"it just started with this constant pain in my hip and going down my leg and it just got worse, it affects my sleep and it's just like a needle going into my hip, basically all of the time" [P4]*

Many patients reported frustrations with their physical limitations, especially where their symptoms left them unable to perform day-to-day tasks and interfered with their ability to work.

*"... I just want to get a bit of my life back because I do struggle with my housework and things I like to do..." [P5]*

*"Oh, it's just a struggle to move. I mean, I work full-time and, you know, I'm limping all of the time with it, because its, you know, I can't walk far (pause), I can't sort of do a lot because of it, because it's just too painful. I certainly can't, you know, go walking or anything" [P4]*

However, not all participant's stories were the same as there were a minority (2/10) who reported no restriction to their physical activity levels.

*"I have no pain at all when I'm mobile and walking around, it's just when I'm sat" [P2]*

Participants (6/10) commonly reported that they were managing co-existing causes of musculoskeletal pain such as low back pain. This often resulted in the participants being managed by different healthcare practitioners, or in different teams within the same hospital.

*“It started with a bad back and I went to an osteopath, and it was something to do with my back, but then I started getting pain in my groin....and then I had my hips replaced in March...” [P1]*

*“I was under the care of the back-pain team at the time, and I did speak to them about it (the hip pain), but they never did any examinations or tests...” [P10]*

### **Understanding of the problem and pain**

Most participants (8/10) linked their pain to anatomical pathology and all had undergone at least one form of radiological imaging. Despite this however, participants remained confused about the cause of their pain. Participants often felt they had been given insufficient information, or diagnostic labels that did not mean anything to them.

*“Well I haven’t been told anything (about the source of the pain) ...so I don’t really know” [P1]*

*“It’s tendinitis isn’t it? ...the latest letter says it’s also right hip ITB syndrome, does that make any sense to you? ...I’ve got loads and loads of letters and looked at it lots of times...every time I go (to the hospital), different people see me, and they come back with different comments” [P3]*

One diagnostic label that recurred was a diagnosis of trochanteric bursitis and the understanding that the cause of the pain was inflammatory.

*“Well initially I was told it was an inflammatory problem, because the pain would flare up and go away...” [P2]*

### **Experiences of previous treatment**

The clinical premise that GTPS is an inflammatory condition was further evidenced by the use of corticosteroid injection as a first line treatment. The majority of patients (7/10) had received previous injections and many of them had received multiple injections which, at best, provided short-term relief.

*“...they said it was bursitis and then I had three injections. Three lots. The anaesthetic one, then two lots of steroids...didn’t do much (in-terms of symptom relief)” [P7]*

Many participants had experienced previous physiotherapy without lasting success. Lack of success with physiotherapy was attributed to many reasons including, lack of belief about the effectiveness, lack of compliance with treatment and the pain caused by exercise.

*“I think I had about three different ones (physiotherapists)...and they were also the ones who did the hydrotherapy and acupuncture as well... but the exercises were just putting me in pain, so it didn’t help” [P10]*

*“...I have never been very good at doing the physio, partly because I wasn’t convinced it was doing the right thing...I’m a terrible patient (laughs)” [P3]*

A common complaint with previous consultations was that participants felt they were dismissed, or that their questions were not answered sufficiently. This was often a source of frustration about the care they had received and left participants feeling that they had not been taken seriously.

*"Nobody's actually told me what causes it or anything; you know, they say 'it's a bursa', but that's about all they say" [P4]*

*"I was disgusted (by the Consultation with the Doctor) because my life is, is, my whole life and social life is stopped because of the bursitis and he just said take the pain killers, well, I take medication and I don't want to take any more" [P7]*

*"...he (the Doctor) didn't seem to want to answer any of my questions...my reasoning is that I didn't think it was due to lack of muscle, he didn't want to entertain that, he just said you need to go to physio" [P10]*

### **Beliefs about activity and exercise**

Despite six patients having previously experienced physiotherapy, most participants remained positive about the potential of exercise therapy to improve their condition and were even happy to tolerate discomfort during it (8/10). This was often caveated with the associated desire to understand when symptoms indicated that exercise was detrimental.

*"Oh, good Lord yeah. Anything that would help I'd go for...If they told me that it would help (exercise with discomfort), I would do it. (When asked what information would be useful) Would it be detrimental if I pushed myself that little bit further?" [P8]*

*"I've got no problem (with exercise) if that's the way to go, yeah that's fine...I'll work through them because practice makes perfect... (When asked what information would be useful) I haven't got any knowledge whether I'm doing the right thing or not" [P9]*

However, not all participants (2/10) would find some discomfort with exercise acceptable, as pain elicited during exercise lingered significantly in some cases.

*"I wouldn't do it (put up with discomfort during exercise). And that is purely because if it affects my day to day living... it's just not worth it" [P6]*

## **The future**

Participants were mixed on the issue of their prognosis when asked whether they were confident they could recover within 6-months. Patients who were positive (3/10) tended to have confidence in the clinicians they had seen or did not feel the condition was serious in nature.

*"Yes, I think so...I think it's just some niggly thing on the hip, something to do with the tendons or something. Yeah, I think you'll be able to sort it out" [P8]*

*“From what the lady that did the injection yesterday said, she did give me confidence that she got bang on the spot, so I’m confident that it is going to work” [P4]*

However, some patients were either uncertain or pessimistic about their chances of recovery. These participants were more likely to have persistent symptoms.

*“To be honest, I don’t know (that the pain would resolve within six months) ... I would like to be able to reduce the pain, erm, but if it’s something that I’ve got to live with then you know, I’ve got to abide by what I can do and what I can’t do”. [P9]*

*“I’m not sure, it took 3 years to get to this... so I’m not sure six months will help” [P7]*

## **DISCUSSION**



This study aimed to provide insight into the experiences and perceptions of people living with GTPS for the purpose of gaining understanding which could inform a programme of intervention development for testing in a future randomised controlled trial.

The findings suggest, that for some individuals, GTPS has a significant impact on their lives; limiting their ability to be active and to rest comfortably. Despite wanting to understand the cause of their pain, participants were often confused about the diagnostic labels they were given and what this meant in terms of their activity levels and recovery. Participants were mostly positive about exercise as a means of improving their condition, however they were often uncertain about how to interpret the pain they experienced during activity. Lastly, many were either uncertain or pessimistic about their prognosis.

Analysis of this data generated two over-arching themes which can inform intervention development in the future; (1) The impact of living with GTPS (2) confusion around diagnosis, pain and activity. The key themes are now discussed in relation to the need for improved interventions for NHS patients with GTPS.

### **The impact of living with GTPS**

This study highlights that the pain associated with GTPS can be disabling and affects patients during basic activities of daily living. It was common for participants to report difficulty with activities such as walking and getting out of a chair as well as interference in their ability to enjoy their hobbies and perform at work. This level of disability supports previous research which suggests that patients with GTPS experience high levels of pain and poor quality of life (Fearon et al., 2017; Stephens et al., 2019). Participants in this study commonly reported having their symptoms for a long period of time and many had experience of previous unsuccessful treatments. Patients with persistent musculoskeletal pain and high levels of disability are at risk of poorer outcomes and are less likely to respond to treatment (Valentin et al., 2016; Artus et al., 2017).

Participants in this study were not only limited in their ability to be active, but also to rest. Patients commonly reported difficulty with sitting and lying comfortably as well as sleep disturbance. This is perhaps atypical of many lower limb tendinopathies and pain conditions. Spinal pain more commonly disturbs patients at rest; and where sleep is disturbed, patients experience poor quality of life, high levels of pain and emotional distress (Strine and Chapman, 2005; Breivik et al., 2006; Jank et al., 2017).

This study supports previous data which suggests that GTPS can be a persistent, debilitating and condition (Woodley et al., 2008; Fearon et al., 2017). The data from this study suggests that future interventions for patients with GTPS should look to target physical disability, discomfort at rest and improving sleep quality for those who require it.

### **Confusion with diagnosis, pain and activity**

This study highlights that some patients with GTPS are left confused by the diagnostic labels which are given to them, despite the frequent use of radiological imaging. One diagnostic label which was recurrently given to patients to explain their symptoms was trochanteric bursitis. The continued use of trochanteric bursitis as a diagnostic label and cortico-steroid injection as a treatment for GTPS, is not supported by contemporary evidence (Rompe et al., 2009; Brinks and Denman, 2011; Long, Surrey and Nazarian, 2013).

Even in cases where patients had been given a clear label such as trochanteric bursitis, commonly this had little meaning for patients and caused further confusion. This is common to many conditions of musculoskeletal pain (Darlow et al., 2013; Cuff and Littlewood, 2017). There is some evidence that patients who are unable to make sense of their symptoms, or who are given patho-anatomical labels to explain their pain, are more likely to interpret their symptoms as a sign of damage (Van Wilgen et al., 2008; Cuff and Littlewood, 2017). This is commonly associated with avoidant behaviours, low

self-efficacy and poor outcomes for a variety of musculoskeletal pain conditions (Asghari and Nicholas, 2001; Bunzli et al., 2015; Chester et al., 2018). Another factor associated with poor outcomes for patients with musculoskeletal pain conditions is poor expectations of recovery (Hayden et al., 2019). Interventions which have helped improve patients re-contextualise their pain, has been linked with improved expectations and outcomes from treatment (Mittinty, et al., 2018).

Patients in this study commonly lacked the confidence to be active and desired more information about the meaning of their symptoms in relation to activity and potential tissue damage. They were also often pessimistic about their chances of recovery. Future interventions for patients with GTPS should look to address issues relating to the diagnostic labels patients are given; the relationship these labels have with symptoms and what this means in terms of activity and potential recovery.

#### **Need for improved interventions for patients with GTPS.**

A recent randomised controlled trial (LEAP) suggests that exercise and education interventions are an effective treatment for GTPS (Mellor et al, 2018). However, the findings in this study, support previous research which suggests patients seeking care within the NHS with GTPS, have complex presentations, that increase risk of poor outcomes (Stephens et al., 2019).

Analysis of the interviews of patients with GTPS, suggests that they commonly experience pain which limits their activity and ability to rest and sleep comfortably. They can experience associated low self-efficacy and can be pessimistic about their potential to recover from the pain.

This study supports previous research in suggesting that GTPS is a complex multi-dimensional pain complaint and that treatment interventions may need to address this complexity to optimise outcomes for patients with the condition. This new understanding of the lived experiences of patients with GTPS can help guide intervention development in the future.

## **Limitations**

The use of pre-determined themes and a mostly deductive approach to data analysis could mean that the analysis is closed and that other emerging themes have been missed. However, open coding and inductive analysis were used by the author group to limit the chances of this occurring.

A contradiction which emerged from the data is that patients were positive about exercise as an intervention to improve their condition; often despite previous unsuccessful physiotherapy and uncertainty surrounding their diagnosis and prognosis. The responses participants were willing to provide, may have been affected by the fact that all interviews were conducted by the same, male physiotherapist. However, it was apparent that participants felt able to discuss their previous treatments in both a positive and negative light which might suggest the role of the researcher did not have a negative influence. Having a PPIE group involved in generating the thematic framework and one member as part of the author group also enhanced the trustworthiness of the data.

Lastly, twenty-seven patients were approached to achieve a sample of ten participants, and it could be that those who have either suffered for the longest time, or suffering the most, were more likely to want to share their experiences.

## **CONCLUSION**

Patients with GTPS, in this study commonly reported that the condition limited their ability to be active and to rest comfortably. Participants were often confused about the diagnostic labels they were given and what this meant in terms of their activity. Participants were uncertain about how to interpret the pain they experienced during activity and uncertain or pessimistic about their prognosis. This study suggests that future interventions to treat patients with GTPS in the UK NHS should consider targeting the physical disability, discomfort at rest and disturbed sleep associated with the condition. Further consideration should be given to education strategies which address diagnostic uncertainty and the meaning of the symptom's patients with GTPS experience in relation to activity and their potential recovery.

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